Rehabilitation in Disseminated Sclerosis:
An Evaluation of 28 Patients

W. O. GEISLER, M.D.* and A. T. JOUSSE, M.D.,† *Toronto*

ABSTRACT

The results of rehabilitation have been described and evaluated in a group of 28 patients moderately severely disabled with disseminated sclerosis between the ages of 19 and 71 years and in a controlled hospital setting. Twenty-three suffered chronic progressive disease and five were in remission from an acute exacerbation. They had had the disease an average of 12.7 years and were hospitalized an average of 5.4 months. On admission, 24 required much assistance with their activities of daily living, six had poor control of elimination, and four were depressed. On discharge, 13 cared for themselves with little or no help, four had overcome their problems of elimination, and three had improved emotionally. A major symptom in 13, fatigue, did not preclude successful performance, but a progression of disease or failure to react steadfastly did. None were gainfully employed. Six years after discharge, 18 of 20 were alive and happy at home.

IT IS now 127 years since the original description of the pathological changes in disseminated sclerosis by Cruveilhier. The cause of this disease remains an enigma,[1, 2] and the care of the patient so affected is not specific. Since the course of the disease is variable and may be prolonged, it is necessary that we show a comprehensive interest in the many aspects of the disorder for each patient committed to our care. Although our management will be general, it must not be impersonal. It is time-consuming. The consequences of this illness try the souls of the doctor and of the patient and his family. Satisfaction is had when one sees a patient progress favourably toward personal independence and restoration of dignity and well-being.

The purpose of this report is to describe and evaluate the results of our endeavours in the rehabilitation of a small group of patients suffering from disseminated sclerosis.

The method was as follows: Data from case histories and questionnaires were transcribed in columns under common headings and reviewed.

The histories of 92 patients were studied. These patients had been seen between January 1948 and January 1961. All patients selected for this review had to fulfil the following criteria: (1) An accurate diagnosis, established beyond any doubt, was required. This was established in each case by a competent neurologist who based his opinion on the history, physical findings and spinal fluid studies. (2) The patient was admitted to Lyndhurst Lodge Hospital, Toronto, for active management because of moderate or severe disablement. (3) The patients were examined individually by one or other of the authors. As a consequence, 64 cases were eliminated, and the data to be reported in this communication pertain to the remaining 28. This represented between 1% and 6.5% per year of the annual admissions to Lyndhurst Lodge Hospital.

There were 14 female and 14 male patients. They ranged in age from 19 years to 71 years. Seventeen were in the 35-50 year age-group. Twenty-three were suffering from the disease in its chronic progressive form, while five patients were in a remission from an acute exacerbation. The sex distribution was equal in both groups. There were 12 females and 11 males in the former and two females and three males in the latter group. The onset of neurological symptoms had occurred as early as 12.5 years and as late as 55 years of age. In 22 patients it had occurred between the ages of 18 and 36 years. The interval between the time of onset and the time when the disease had progressed to the stage of moderate or advanced disablement varied between one and 41 years, the average interval being 12.7 years. In 18 patients the interval was between five and 15 years, while in seven it had extended beyond 15 years. The period of hospitalization for rehabilitation was from two weeks to 17 months, the average period being 5.4 months.

The methods of rehabilitation were comparable to those employed in the management of patients suffering from other types of major neurological disability. These included active and passive individual exercises; group calisthenics; mobilization of spastic limbs by stretching and serial splinting; peripheral nerve blocks with procaine or lidocaine (Xylocaine) to facilitate mobilization; selective tenotomies and neurectomies to abolish deforming tendencies of spastic muscles; subarachnoid injection of absolute ethyl alcohol to abolish spasm in the legs and bladder; instruction in self-care; instruction in bladder and bowel control; investigation of interests and aptitudes; advice and help in re-planning living quarters; and a cautious redirection of the patients'

Presented at the 9th Annual Meeting of the Canadian Association of Physical Medicine and Rehabilitation, Saskatoon, Sask., August 25, 1961.
*Clinical Teacher, Department of Rehabilitation Medicine, University of Toronto, and Assistant Medical Director, Lyndhurst Lodge Hospital, Toronto.
†Director, Department of Rehabilitation Medicine, Faculty of Medicine, University of Toronto, and Medical Director, Lyndhurst Lodge Hospital, Toronto.

thoughts to more realistic goals. Constantly the patients were encouraged to persist in reasonable endeavours and to hope for success in spite of setbacks and discouragement.

The results of these methods are shown in the accompanying scattergrams (Fig. 1).

Each scattergram depicts the status of the patient at the time of discharge with respect to (a) his physical accomplishments, (b) his control of bladder and bowel, and (c) his emotional reaction. Each dot represents a patient. Each column is divided into fifths. The central fifth denotes those whose status at the time of discharge was unchanged from that on their admission. The upper areas indicate those who showed improvement, and the lower areas those who showed progression of disablement.

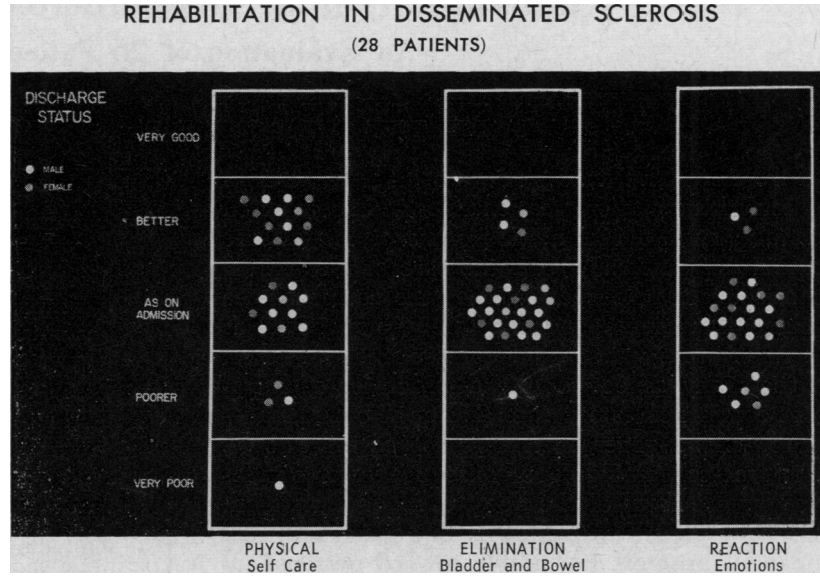

Fig. 1.—Distribution of discharge status following rehabilitation in 28 patients with moderately severe disseminated sclerosis treated between 1948 and 1961.

At the time of admission almost all required more than a moderate amount of help to perform the usual activities of daily living. At the time of discharge 13 had shown worthwhile improvement and required little or no help; four had become worse. In three of the latter this was due to progression of the disease and in one it was due to severe fatigue.

At the time of admission 22 patients had acceptable methods of elimination, while six were in moderately severe difficulty in this respect. At the time of discharge four had improved following transurethral resection of the bladder neck, pudendal nerve block or sacral rhizotomy. One had become worse owing to progression of the disease, and two remained disabled but also deteriorated emotionally.

At the time of admission the emotional reaction of the patients was in accord with what one would expect in the face of moderate disability. Most were despondent, a few depressed and a few elated. At the time of discharge, three had learned to accept their difficulties more graciously and were able to return to their homes. Two of these had improved physically and in the management of their bladder and bowel. Six showed deterioration. Of these, five had severe or prolonged progressive disability and one was felt to be immature.

Among the 16 who fared best, the following observations were noted. Ten were female and six male. Eight were married and eight were separated. They had had their disease on an average of 11.9 years, and a progressive type predominated. They had been hospitalized 6.1 months. Fatigue was a prominent symptom in five. There was not necessarily concordance in improvement in the three categories. The emotional status had improved in three, remained unchanged in 10 and had worsened in three. Fifteen were discharged to their homes and only one to a place for domiciliary care when his family refused to shelter him.

Of the nine who regressed, five complained of recurring severe fatigue. This symptom was reviewed with reference to all 28 patients. It was a major and recurring symptom in 13. Seven were female and six male. Eleven of the 13 suffered from a progressive form of the disease. Physically, eight improved, three deteriorated and two were unchanged. Emotionally, one improved, three regressed and nine were unchanged. In every case deterioration paralleled the progression of disease. Eight were able to return to their homes and carry on, and five were admitted to institutions for domiciliary care. It does not follow, then, that fatigue alone will diminish the possibility of success.

A recent study of quadriplegic and paraplegic patients has shown that, regardless of the extent of disability, the higher the level of academic attainment the better the prospect for gainful employment.[3] Indeed, over 90% of the university graduates and 60% of the high school graduates were working. This was not observed in the present study. Twenty-two had completed a course of formal academic instruction. Five had completed public school only. Ten had completed secondary school curricula, six had completed vocational school training and one had completed university. In no instance was the return to gainful employment accomplished, although nine of the 22 had shown physical improvement. Four women did return to their housework; a graduate pharmacist and a school teacher became active in magazine subscription businesses; however, they could not support themselves. Six months after discharge the teacher died, and within two years the pharmacist was admitted to a place for domiciliary care because of progression of his disease.

Eight patients were admitted sooner or later to a place for permanent domiciliary care. Five were single and three married. Three went directly to domiciliary care settings on discharge when their families could not or would not have them home, and one of these died within a year. Five more were admitted as progressive disablement rendered home care too great a burden, within five years of discharge. Twenty patients returned home. Eighteen were alive, happy and well six years later. Two had died.

DISCUSSION

The admission rate of 6.5% per year of admissions to a rehabilitation hospital indicates careful selection of cases in this series. Only the moderately severely disabled were admitted. The majority had had their disease a long time (12.7 years); the ratio of the progressive to the relapsing type of disseminated selerosis was 4:1. The equal sex distribution is not remarkable. The average period of hospitalization of 5.4 months is reasonable, considering the degree of disablement in these patients. By comparison the average stay in the same hospital for paraplegics is 4.4 months and for quadriplegics 10.5 months.

In evaluating our endeavours, we believe that in the patients who fared poorest a progression of the disease and a failure to react steadfastly were the major contributing factors. The adaptability of one's personality to illness depends upon one's character and intelligence. The belief that fatigue will condemn the patient to failure is false and must be dispelled. If gains are made in personal independence, and if his family, friends and doctors continue to provide him with their support, he has a better than 50% chance of returning to his home. If a plan for reasonable living in spite of disability can be outlined to the patient and family and can be appreciated by them, the fears of the family of being burdened may be dispelled. This requires a good deal of ingenuity on the part of the doctor and his associates.

To attain physical independence in order that one may live with severe disability requires tremendous fortitude, and energy expenditure must be high. Perhaps this is already maximal, and energy for gainful employment is not available. The uncertainty of the future for the patient militates against any but self-employment, for these patients are rarely able to assure regular attendance at work through skill and endurance.

It is generally recognized that in patients with disseminated sclerosis the average length of life from the development of first plaque is 25 years.[4] We were seeing most patients, then, after the midpoint in their course. We had no illusions of prolonging life. We did hope that our efforts would make their remaining years more bearable without burdening the family or displacing affection. We believe those efforts have been worth while.

We have presented this report not because of any new form of treatment or special results obtained, but because this series of patients has permitted reporting the results of treatment in a controlled setting by methods which have proved valuable in the treatment and rehabilitation of patients with other neurological disorders.

SUMMARY

Fifty-seven per cent of a group of 28 patients moderately disabled by disseminated sclerosis benefited appreciably from active treatment in a rehabilitation hospital. Their average age was 41.3 years. They had had their disease an average of 11.9 years and were hospitalized for an average of 6.1 months.

REFERENCES

1. MILLER, H.: *Proc. Roy. Soc. Med.*, 54: 7, 1961.
2. LUMSDEN, C. E.: *Ibid.*, 54: 11, 1961.
3. JOUSSE, A. T.: Personal communications.
4. PARSONS-SMITH, G.: *Brit. J. Clin. Pract.*, 13: 479, 1959.

PAGES OUT OF THE PAST: FROM THE JOURNAL OF FIFTY YEARS AGO

MEDICAL EXPERT TESTIMONY

From the earliest times the services of physicians have always been required by courts of justice in those cases, particularly, in which a decision is necessary as to the sanity of a criminal and the extent of his responsibility, or as to the mental capacity of a testator at the time of making a will, and in cases requiring postmortem examinations. But owing to the industrial developments of recent times, and the recognition of the responsibility of employers for their servants and of transportation companies for the safety of the public, the preponderance of medico-legal practice has to do with cases of this nature, and expert testimony is consequently much more frequently called for now than formerly. . . .

Medicine is not an exact science nor a perfect art. There is room for much difference of opinion, for example, as to the damage, physical and above all psychical, suffered by an injured person, and as to the degree of his resulting incapacity. Yet the expert may be called on to give a definite prognosis in a case, perhaps, which he is seeing now for the first time, months after the accident. Then comes the cross-examination with its undoubted abuse of the hypothetical question. Contradictory evidence is elicited, and one authority quotes against another. Furthermore, the medical expert may be perfectly competent and perfectly honest in his endeavour to express unbiased opinions, but being retained and paid by one party to the suit, he necessarily studies the facts of the case from the point of view of that party, and it is humanly almost impossible for him to be impartial in his judgment. He becomes, in fact, an advocate. . . .

We are strongly of the opinion that the commission or some similar method of obtaining expert evidence should be resorted to in all medico-legal cases.—Editorial, *Canad. Med. Ass. J.*, 3: 47, 1913.